327 The adult cystic fibrosis patient: education, sports and work

A. de Vrankrijker[1], I. Drubbel[1], C. van der Ent[1], F. Teding van Berkhout[1], H. Heijerman[2]. [1]*University Medical Center, Utrecht, Netherlands;* [2]*Haga teaching Hospital, The Hague, Netherlands*

Objective: Over the past decades, survival of CF patients in the Netherlands has improved. More patients reach adulthood and have to arrange their lives in terms of education, work and free time. It is not fully clear in what way this is restricted by their illness. This study aims at assessing the current participation of adult CF patients in education, sports and work and whether or not this is related to their pulmonary condition.
Methods: A questionnaire was sent to all adult patients registered at the CF centres of Utrecht and The Hague in October 2005, featuring questions on educational level, employment, sports and daily activities. Data extracted from the returned questionnaires were linked to FEV_1% predicted data as registered in the database of the centres.
Results: 51% of patients returned the questionnaires. All these patients reported to have completed a certain type of education, 65% of which have had tertiary education. 30% of patients report having had an educational delay. 45% report being employed, 25% work full time. A wide range of occupations is seen. No relationship between employment and pulmonary function was found. 90% spend at least 30 minutes on physical activities every day. This also shows no relationship with lung function values.
Conclusions: CF patients spend ample time on sports and other physical activities, regardless of their pulmonary status. The reported educational level is generally high, although educational delay is common. CF patients find employment in various occupations, working part-or fulltime. In conclusion, CF has a major impact on adult life, but provided working and educational conditions are flexible, many patients find a worthy contribution to both economical and social activities.

328* Psychosocial case study: infant diagnosed with CF through newborn screening

A. Tluczek. *School of Nursing, University of Wisconsin, Madison, WI, USA*

This case was identified through a study examining the impact of cystic fibrosis (CF) newborn screening (NBS) on parents, their infants, and the parent-infant relationship. Some facts have been altered to protect the family's confidentiality. Following an uncomplicated pregnancy, labor, and delivery, a male infant was the first-born to a middle-class married couple. The infant was diagnosed with CF at 2 weeks of age following abnormal NBS and sweat tests. The child had a normal chest x-ray and no pulmonary symptoms; enzyme therapy was initiated to treat pancreatic insufficiency. A 3-month assessment showed a healthy infant who was at the 25th percentiles for weight and height. His mother had a score of 18 on the Center for Epidemiological Studies Depression Scale (CES-D) which is slightly above the clinical cut-off of 16 and her score on the State scale of the State Trait Anxiety Inventory (STAI) was at the 85th percentile. The Parenting Stress Inventory (PSI) showed her scores to be in the clinical range for the Parent Domain subscales of Spousal Relationship and the Infant Domain for Mood, Adaptability, and Acceptability. Observations of the mother-infant interaction during feeding showed few social initiatives, constricted affects, and little eye contact. The father's score on the CES-D was 10 and at the 35th percentile for the STAI. He had PSI scores in the clinical range on the Parent Domain Attachment subscale and the Infant Domain subscales for Mood and Reinforces Parents. Both parents described the infant as a "fussy baby" who was difficult to soothe. During a qualitative interview the father described the diagnosis as "devastating". They added that they found the CF Center team to be their main source of support. Discussion will address whether to refer this family for services and if so what kind of services.

329 Gift of life: Young adult lung transplant recipients talk about their new lungs

G. Ullrich[3], S. Schmidt[2], E. Scharf[1], J. Penkert[1], J. Niedermeyer[4], W. Schulz[1]. [1]*Institute of Psychology, University of Braunschweig, Braunschweig, Germany;* [2]*Clinical Research Hanover (Prof. Steinkamp), Hanover, Germany;* [3]*Paediatric Pulmonology, Hanover Medical School, Hanover, Germany;* [4]*Internal Medicine & Pulmonology, Hanover Medical School, Hanover, Germany*

Psychosocial studies on lung transplantation (LTx) mainly address issues of quality of life and of psychosocial functioning. Amazingly, the most distinguishing aspects of LTx are rather neglected (donorship issues and the integration of the new organs, herein referred to as the OTHER). We therefore aimed at addressing these aspects in young adult recipients with at least 12 mo post transplant survival.
Methods: semistructured interviews; content analysis; the latter was restricted to the following parts of the complete interviews: (a) the OTHER, (c) attitude towards living donorship, (d) attitude towards candidates who reject the option of LTx, (e) attitude towards a possible own redo-LTx.
Sample: 45 double LTx recipients (27 with CF, 18 with other lung disease), aged 18 to 42 years ($x = 32 \pm 5.5$ y), who were transplanted 1 to 11 years ago ($x = 5.3$ y and 5.8 y, respectively).
Results: 60% of all recipients tried to skip the OTHER from concsiousness, 7% appeared to be affected, 11% described their experience rather neutrally, and 22% noticed the OTHER in a positive way. The forthcoming option of living donorship in LTx rather appeared to aggravate conflicts of acceptance and 28% said that the possibility of severe donor impact would disqualify this option. The vast majority of recipients (79%) understood that the OTHER might as well be a reason to opt against LTx. However, with respect to a possible own redo-LTx 73% were extremely clear in favour of it.
Conclusions: LTx recipients try not to be bothered by gift of life issues and are strongly convinced of this option.

330 Telephone calls received by CF nurse specialists – best use of a scarce resource?

H. Miller, P. Dyce, B. Govin, C. Cowperthwaite, M.J. Ledson, M.J. Walshaw. *Regional Adult CF Unit, The Cardiothoracic Centre, Liverpool, United Kingdom*

CF nurse specialists are core members of the multidisciplinary team, and have a wide ranging role supporting all aspects of CF patient care. As such they are often under great pressure but despite this their duties may be under constant scrutiny within a resource limited health care service. However, many duties, including telephone support, are not easily monitored. We audited direct telephone calls received by our CF nurses, looking at the identity of the caller, call length, nature of the enquiry, and the work generated by the call.
Over 2 months, 288 calls were logged (total 924 minutes, average 23 calls per day) (see table): 25 related to transition, 35 outpatient appointments, 60 general CF issues, 25 home IV therapy, and 10 holiday matters. As a result of calls, 7 patients were admitted, 5 assessed as ward attendees, 43 out patient appointments were made or amended, 8 meetings were set up and 14 prescriptions arranged.
This audit shows that a considerable amount of time is taken up by telephone calls to CF nurses, much of which could be dealt with by suitable clerical support. Such help would allow the skills of a CF nurse specialist to be better utilised, for the benefit of this patient group.

Source	Number	Duration (minutes)	Followup (%)
Wards	8	16	0
Nurse specialists	28	100	54
Home IV service	24	57	42
Relatives	38	232	55
Medical staff	5	5	60
Patients	96	290	77
External agencies	18	102	78
Others	71	134	58